



Department of Health & Social Care

*From Maria Caulfield MP
Parliamentary Under-Secretary of State for
Mental Health and Women's Health Strategy*

*39 Victoria Street
London
SW1H 0EU*

Our ref: PO-1489124

Ms Sammie McFarland
CEO
Long Covid Kids
By email to: j.ryan@bhattmurphy.co.uk

21 February 2024

Dear Ms McFarland,

Thank you for your correspondence of 6 December to the Prime Minister, co-signed by Professor Mark Faghy, Ondine Sherwood and Jo Dainow, about investment in long-COVID research. Your letter has been passed to this department and I apologise for the delay in replying.

I am grateful to you and your co-signatories for raising your concerns.

As you know, the Government has invested over £50million through the National Institute for Health and Care Research (NIHR) and UK Research and Innovation (UKRI) in long-COVID research projects. These projects aim to improve our understanding of the underlying mechanisms of the condition and the effectiveness of pharmacological and non-pharmacological therapies and interventions.

Following this early investment, we have continued to support long-COVID research through programme funding and infrastructure support. Further information on our long-COVID research portfolio can be found by searching for 'long COVID' on both the NIHR and UKRI websites.

Long COVID is a new and complex multi-system disease, likely comprised of a number of syndromes with different underlying mechanisms. For any new disease, development of new drugs is a long process, often taking 10-15 years to reach the treatment stage. For this reason, the first clinical trial for pharmacological treatments in the UK focused on 'repurposed' medicines, which can be more rapidly tested in a platform trial. More information can be found at fundingawards.nihr.ac.uk/award/COV-LT2-0043. Further mechanistic and clinical characterisation research is required to support clinical trials. For example, research on identification of biomarkers and diagnostics for long COVID is essential to support development of new treatments.

The NHS and scientific community are working rapidly, but we recognise that the pace of research to find new treatments is frustrating, especially for those most severely affected. For this reason, we hosted the event in March 2023 to provide a broad overview of the long-COVID research landscape in the UK and facilitate future collaboration between researchers. The group recognised that there is a need to examine long COVID in children

and young people as a distinct group. We would like to take the opportunity to thank the researchers and people with lived experience for taking part in this event. More information can be found at www.nihr.ac.uk/documents/output-from-the-nihr-long-covid-networking-event/34537.

As findings emerge from current research, we encourage researchers to apply for funding to build on and develop the newly established infrastructure, partnerships and resources, sustaining collaborative activities and research capabilities. Collaborative bids between study groups are likely to be competitive, including international collaborations, cohort studies and systematic reviews. Government research funding staff are available to support long-COVID researchers in their applications for funding.

It is not usual practice to ring-fence funds for expenditure on particular topics. Research proposals in all areas compete for the funding available and we welcome funding applications for research into any aspect of human health. These applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.

In all disease areas, the amount of funding depends on the volume and quality of scientific activity. When considering applications for funding, researchers should review the 'remit pages'. The most suitable programme for long COVID would depend on the research area, the scale of the study, and whether it will generate new evidence or build upon existing evidence. There is scope for significant further 'basic' or 'early phase' long-COVID research, which would be best supported by the UKRI councils. For clinical trials specifically, there are two large NIHR programmes offering funding, and information can be found at www.nihr.ac.uk/explore-nihr/funding-programmes/efficacy-and-mechanism-evaluation.htm and www.nihr.ac.uk/explore-nihr/funding-programmes/health-technology-assessment.htm. UKRI offers funding for clinical trials through the Medical Research Council. More information can be found at www.ukri.org/what-we-do/browse-our-areas-of-investment-and-support/clinical-and-translational-research.

Regarding public awareness, information on COVID-19 and long COVID is widely available from the NHS and from the Government in a variety of formats, providing consistent messaging for the public. This includes information for all age groups on symptoms and healthcare support available, as well as information regarding long-COVID studies that are currently recruiting new participants. Information is also available for those who have long COVID and are unable to work, or who need support to find, return to or stay in work.

Education and childcare settings should encourage any parent, guardian or carer that has concerns about their child and long-COVID symptoms to consult their GP, who will be able to refer them for an assessment if appropriate or talk to the school nursing service.


Research on long COVID is ongoing and will give us a better understanding of its prevalence, severity and duration. Work is taking place across Government to understand the impact of long-COVID symptoms on areas such as absence, learning and workforce. The Department for Education continues to work with other Government departments and

agencies, like the NHS, to share important information with the education and childcare sectors in a timely manner.

In terms of service provision, funding for adult post-COVID services is being provided recurrently by the NHS in England, and the funding for specialist post-COVID children's and young people's hubs has also been identified for each region for the 2024/25 financial year. NHS England has published guidance that aims to assist local healthcare systems to plan and deliver services that meet the varied and often complex needs of people living with long COVID, which can be found at www.england.nhs.uk/publication/national-commissioning-guidance-for-post-covid-services. NHS England remains committed to ensure the delivery of high-quality post-COVID services across the country.

I hope this reply is helpful and I would be grateful if you could share it with your co-signatories.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Maria', with a stylized initial 'M'.

MARIA CAULFIELD MP